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## Conducting research with African elderly persons: Is their vulnerability a concern to researchers?

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### Abstract

The African elderly population is currently estimated to be slightly over 38 million. In order to provide best practice and quality management strategies, health care professionals need to conduct research that can assist in ameliorating age specific conditions and improve the quality of life of elderly persons. However, risks abound when studying elderly persons. They may suffer from deteriorating physical and or psychological conditions associated with the ageing process raising concerns of vulnerability with their participation in any research contentious. The increase in social research conducted as a result of HIV/AIDS raises further concerns about the ethics of conducting research on elderly African persons with regards to issues of autonomy and informed consent. This paper examines the ethics and the notion of vulnerability of African elderly persons within the context of research. A literature review on the vulnerability of elderly persons and considerations for research provided the analysed data for this paper. Access to the database were mainly via EBSCO (www.ebsco.com) containing electronic databases useful in an academic setting for finding and accessing articles in health and health related academic journals, repositories and archived reports. Findings show African elderly persons are a vulnerable population and specific strategies and the implications for ethics are provided for use when conducting research on the elderly population.

**Keywords:** Elderly persons, research vulnerability, ethics, developing countries.

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### Introduction

The population of elderly persons has risen in recent years bringing with it an increase in research on physical ageing, elderly disease conditions, investigations into the effectiveness of social programmes and services, and marketing research to influence decisions in this growing market sector (Walsh, 2009). Globally there is estimated 600 million people over the age of 60-years, and this population is expected to double by 2050 (Chucks, 2004; Pienaar, Swartdt, De Vries & Roos, 2004). The African elderly population, currently estimated to be slightly over 38 million, is projected to reach between 203 and 212 million by 2050 (Help Age International, 2002). In a population where there are resource scarcities, aging has the potential of becoming a major issue, as the older population is expected to continue growing in the next two to three decades. The increasing number of elderly population is

propelling research in multiple disciplines in an effort to describe, understand and treat problems of aging.

Research can have potential risks to harm participants particularly the vulnerable ones (Walsh, 2009). The elderly are not inherently a vulnerable population but their vulnerability is context-specific as they may be at risk due to age, health, functional status, chronic illness, and financial circumstances (Agency for Health Care Policy and Research 1998; NBAC, 2001). Evidence of their vulnerability in physical, psychological, economic and social forms is noted in literature (McMurdo, Witham & Gillespie, 2005; Makiwane & Kwizera, 2007; Karlawish, Rubright, Casarett, Cary, Ten Have & Sankar, 2009). The inclusion of elderly persons in research warrants special precaution since they are vulnerable subjects. In this paper vulnerability of elderly persons, ethical principles as well as strategies that can be applied in conducting research in the African older persons' population are discussed.

### **Methodology**

A literature search on the vulnerability of African elderly was performed through a multiple electronic data base, using the combined key words of elderly, older person, vulnerability, ethics, consent and research. An additional manual search was done to obtain articles in the reference list of published works identified through the electronic search. The search was limited to studies in academic literature referring to the elderly, emotional, physical, social and health, as well as reports written by organizations related to vulnerable population. Access to the database were mainly via EBSCO (www.ebsco.com) containing electronic databases useful in an academic setting for finding and accessing articles in health and health related academic journals, repositories and archived reports. Sixty- eight (68) articles were selected, reviewed with the contents synthesised along the following areas considered most relevant to research and Africa elderlies' vulnerability:

- Elderly persons as vulnerable population
- Application of western principles on African participants
- Ethics of vulnerable population
- Elderly persons as a vulnerable population

The elderly people are considered a vulnerable group in society (Suhonen, Stolt, Launis & Leino-Kilpi, 2010) and may sometimes have diminished ability to provide informed consent (Grady, 2009). Vulnerable persons are those who are relatively (or absolutely) incapable of protecting their own interests. They may have insufficient power, intelligence, education, resources, strength, and other needed attributes to protect their own interests (Department of Health and Human Services, 1993). Vulnerable population are also described as those that are often already leaving under high-risk health conditions, have limited resources and 'might bear unequal burdens' in research because they are 'readily available' in setting where research is conducted (The Belmont Report: 1978; Nuffield Council on Bioethics, 2003). Age, health, functional status, chronic illness, financial circumstances, (all of which may apply to the elderly) are factors contributory to vulnerability. Suhonen et al. (2010) identified multiple ways that include physical, psychological, economic and social aspects in which the elderly are vulnerable as research participants.

### **Physical vulnerability**

Ageing is often accompanied by multiple physical changes which can impact on health. The elderly are rendered fragile, not only by the diseases they acquire but also by the general physiological decline

that occurs with age (Lang, Michel & Zekry, 2009). The physiological aspects of ageing are compounded where pathological factors are also present and add to physical stresses of the elderly. This population can be influenced by false expectations created by the researchers and therapeutic misconceptions that make them take part in the research in the hopes of getting special treatment often free of charge. Age-related hearing loss which is often associated with depression, social isolation, poor social interactions, poses challenges for the elderly in understanding research information. Thus obtaining valid informed consent from older persons can be more challenging as a result of these impairments (McMurdo et al. 2005).

### **Psychological vulnerability**

A major area of psychological vulnerability amongst older persons is in intellectual functioning. The increasing likelihood of cognitive impairment and dementia amongst elderly people is a particular challenge when it comes to understanding the informed consent (Dewing, 2002; Sherratt, Soteriou & Evans, 2007; Hall, Longhurst & Higginson, 2009). In his argument, Dewing (2002) postulates that a person with altered abilities in communication, memory, language and perception does not that the cognitive effects of a disorder may impair subjects' abilities to protect their interests (Appelbaum, experience the ritual of informed consent from the perspective of an equal participant. The capacities of depressed people to consent to research have been questioned by commentators who fear Grisso, Frank, O'Donnell, David & Kupfer, 1999).

### **Economic vulnerability**

Elderly people are consistently among the poorest in all societies, and when they experience poverty it is likely to be an enduring experience (Makiwane, & Kwizera, 2007). Populations with limited resources are particularly vulnerable as their economic circumstances may limit truly independent consent which may also be distorted through giving of incentives (Creed-Kanashiro, Ore, Scurrah, Gil & Penny, 2005).

The elderly population is not spared from the impact of HIV/AIDS. Literatures show that while the economic consequences for the elderly who give care to the sick and the orphans or have lost children to HIV/AIDS cannot be quantified, its impact is great (Baylie, 2002; Nel, 2004; Kipp, Tindeyebwa, Rubaale, Karamagi & Banjenja, 2007; Bock & Johnson, 2008; Ogunmefun & Schatz, 2009). The declining health and lack of economic security reinforces one another in a vicious circle which makes the elderly persons prey to exploitation by researchers particularly those coming from rich countries. They may unwittingly, as a result of the hardships of poverty, hope that participating in a research will benefit them financially.

### **Social vulnerability**

The frail elderly are also said to be experiencing high social vulnerability according to Andrew, Mitnitski & Rockwood, 2008). This is because more losses occur during old age than during any other period of life. Friends and loved ones die. Life changes such as illness, employment (retiring, loss of job), diminished income, and loss of spouse can also increase their vulnerability. These losses can severely impact all aspects of the research process, including participation, recruitment, and data quality (Uman & Urman, 1990).

Literature shows that vast majority of elderly African persons do not have basic education (Lam, Leibbrandt & Ranchhod, 2004). This low level of literacy amongst older persons raises a concern about their ability to adequately comprehend the research process, and their potential risk for an effective and informed voluntary decision (May, 2002; Makiwane & Kwizera, 2007). The low literacy rate may make the African elderly persons to be easy targets for research as they may have very little awareness of their rights and the risks to which they could be exposed in clinical trials (Beauchamp & Childress, 2001).

The use of western ethical principles on African elderly participants adds another dimension to vulnerability

The application of western principles on African elderly participants adds to their vulnerability. The biomedical research originates from western cultural background and is based exclusively on Western principles (Agulanna, 2010). According to Ravindran (ND), researchers should bear in mind that in an African context individual autonomy and decision capacity are embedded within the social and cultural patterns of family ties and community obligation. Elderly persons being part of the community are apt to want to ask the family if they should be part of the research. Their need to participate in any research is dependent on the collective decision making process. The rights of autonomy and self-determination, in which the principle of voluntary informed consent is rooted seems to be incommensurable with collective values of African culture. Jegede (2009) argues that applying the western concepts of autonomy without adequate consideration for the important role of the community is inappropriate. Given that the principle of voluntary informed consent is putatively rooted in individualistic values (especially rights of autonomy and self-determination) it seems that it would not be ethically and culturally feasible to apply the principle in African communitarian culture (Frimpong-Mansoh, 2008).

### **Strategies for applying an informed consent on older persons**

Multiple approaches are suggested in dealing with ethics of researching older persons. A competency-based approach to informed consent is one way. The emphasis in seeking and maintaining consent in person-centred research, where nurturing personhood is a primary value, based on the principle that persons with dementia are valued and respected as embodied, self-creating social agents. In this approach, the researcher is concerned with relationship and connecting or engaging with the other person with a view to working out consent issues through the relationship (Dewing, 2002). Adopting the community engagement approach in circumventing the problem of individual choice and emphasizing the use of community approval and verbal consent for research in countries where cultural values and practices are valued is proposed (Agulanna, 2010).

Literature suggests many ways that can be adopted in obtaining informed consent from older persons participating in research. This can be done as an integral part of the interview process, using individualised communications in a total 'communication framework' which includes use of graphic symbols (Cambridge & Forrester-Jones, 2003) particularly for illiterate elderly persons. A consent form should be viewed as a continuous process rather than an outcome to be achieved due to the changeable nature of the older persons' competence over time (Booth, 2002).

Accurate and balanced information about the research must be conveyed to the person, who must be capable of making a decision about his/her participation in the research without coercion (Sherratt et al., 2007). In the process of obtaining informed consent older person should be respected and valued and should not be patronized or infantilized. Furthermore their privacy and dignity should be maintained whilst respecting their autonomy (Lin & Chen, 2007). The authors suggest that informers should first assess the diverse layers of culture of the target older persons' population and then develop a form of informed consent. The use of proxy concern is still recommended to provide consent for a subject who is not competent to do so (Karlawish et al 2009).

### **Conclusion**

The elderly are vulnerable in multiple ways, and risks abound when studying older persons. This population may be at risk due to age, health, functional status, chronic illness, and financial circumstances. Elderly persons can be influenced by false expectations created by the researchers and therapeutic misconceptions that make them take part in the research in the hopes of getting special

treatment often free of charge. They may also feel obligated to participate in research fearing that refusal to participate may jeopardize their treatment. Cognitive impairment amongst older people is a particular challenge when it comes to understanding the informed consent. Low literacy among African older persons disadvantages them further as they are unable to understand written information and may not be aware of their rights and the risks involved in the research. Poverty and hardships may force them to participate in research with the hope of receiving financial relieve from researchers.

Application of Western principles of autonomy and self-determination rooted in voluntary informed consent seems to be incommensurable with collective values of African culture, and this contributes to elderly persons vulnerability as they have to participate in a culture unfamiliar to them. The inclusion of elderly persons in research warrants special precaution since they are vulnerable subjects. Different strategies are suggested in dealing with research on older persons. Research should be undertaken with consideration of the culture of elderly persons. Community approach is key for approval. The seeking and provision of consent from older African persons to participate in a research should first be informed by culture and individual differences. The family should be part of accessing such consent. Obtaining consent should be a continuous process. In addition competence to consent should guide the process and where possible proxy consent be sought. Researchers should ensure that older persons understand the benefits and risks of participation. Accurate and balanced information about the research must be conveyed without coercion. There is a need to educate elderly persons with regards to the research process so that they do not feel obligated to be part of the study for the purpose of receiving treatment. The use of proxy concern is still recommended to provide consent for a subject who is not competent to do so. Further research is needed on this topic from the perspective of elderly persons.

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